

## Brief Methodologic Report

### Care Consistency with Documented Care Preferences:

#### Methodologic Considerations for Implementing the Measuring What Matters Quality Indicator

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## Abstract

A basic tenet of palliative care is discerning patient treatment preferences and then honoring these preferences, reflected by the inclusion of “Care Consistency with Documented Care Preferences” as one of ten Measuring What Matters (MWM) quality indicators. MWM indicators are intended to serve as a foundation for quality measurement in health care settings. However, there are a number of logistic and practical issues to be considered in the application of this quality indicator to clinical practice. In this brief methodologic report, we describe how care consistency with documented care preferences has been measured in research on patients near the end of life. Further, we outline methodological challenges in using this indicator in both research and practice, such as documentation, specificity and relevance, preference stability, and measuring non-events. Recommendations to strengthen the accuracy of measurement of this important quality marker in health care settings include consistent recording of preferences in the medical record, considerations for selection of treatment preferences for tracking, establishing a protocol for review of preferences, and adoption of a consistent measurement approach.

## **Introduction**

The Measuring What Matters (MWM) project of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA) outlines ten hospice and palliative care quality indicators to serve as a foundation for quality measurement in U.S. health care settings (1). The MWM indicator, Care Consistency with Documented Care Preferences, was chosen as one of the ten quality indicators, reflecting the importance of assessing care preferences and then following through on stated patient choices for treatments. The indicator was drawn from the ACOVE (Assessing Care of Vulnerable Elders) indicators (2) and is described as follows: “If a vulnerable elder has specific treatment preferences (for example, a DNR order, no tube feeding, or no hospital transfer) documented in a medical record, then these treatment preferences should be followed,” (1).

This indicator is especially important because a key component of palliative care is to help patients and families make complex medical decisions, document these decisions, and ensure that the treatments provided are consistent with these preferences (3). Concordance between patient goals and treatments is critical to improving care of the dying (4). An important marker of patient-centered care is decision quality – ensuring that medical treatments reflect the values and goals of patients who are well informed about clinically appropriate options and outcomes (5).

Although “Care Consistency” is the only MWM quality indicator specifically targeted at the more narrow population of “vulnerable elders,” it is relevant for patients of all ages with advanced life-limiting illness or terminal conditions. This quality indicator has been applied to evaluate the quality of care provided to cohort of adults who died in the hospital. In a 2007 study, Lorenz and colleagues used this indicator to evaluate the quality of care provided to a cohort of adults who died in the hospital. Treatment preferences were followed 96% of the time, but documented advance directives were available for only 18% of patients during the terminal hospitalization (6).

There are a number of logistic and practical issues to be considered in the application of this quality indicator to clinical practice. In this brief methodological report, we will describe how care consistency with documented care preferences has been measured in research on patients near the end of life, outline methodological challenges in using this indicator in both research and practice, and make recommendations to strengthen the measurement accuracy of this important quality marker in health care settings.

### **Background - Measuring Care Consistency with Preferences**

Studies measuring care consistency with preferences at the end of life have yielded mixed findings. Some studies have found that consistency is higher for patients who have a known preference for receiving life-prolonging treatments compared to patients who have a known preference to forego these treatments (7, 8). Other studies have found the converse, that patient preferences for limited treatment and comfort care measures are more likely to be honored than patient preferences for all treatments possible (9). These differences may be due in part to variability in the populations studied, i.e.-a general population of older adults versus people with end-stage disease known to have limited treatment options.

Several factors appear to increase the likelihood that preferences will be followed, including the documenting patient treatment preferences on a living will and appointing a surrogate decision-maker (7, 9, 10). However, the challenges of using living wills to direct treatments, including complex or unclear language, limit the utility of these documents in the clinical setting (11, 12). Physicians also play an influential role in care consistency. In one study, patients who discussed end-of-life wishes with their physicians were more likely to receive consistent care (13). Another study found that the main predictor of patient involvement in decisions to limit life-prolonging therapy was whether the patient agreed with the physician's treatment goals, highlighting the role that physician preferences and beliefs play in

decision-making (14). Patient characteristics may also be associated with care consistency with preferences, as suggested by research indicating that black patients were more likely to receive life-prolonging measures at end of life despite documented preferences for symptom-directed care (13).

The issue of care consistency has been written about extensively in the decision science literature and there is disagreement about the best way to assess care consistency with goals. Winn et al. (5) conducted a literature review which included articles that reported: (a) a measure of patient preference for health outcome or treatment; (b) the intended or actual choice of treatment undergone; and (c) a measure that reported the degree of concordance between the preference and outcome. This review included studies that considered a broad range of medical decision-making, ranging from pre-natal screening, cancer screening, genetic testing, to end of life treatments. The authors describe various methods for calculating value concordance. Concordance was most frequently calculated using “preference for outcomes/attributes” as the independent variable and “treatment intention directly assessed” as the dependent variable. Compared to an earlier review, more studies included a measure of patient knowledge about the decision and its association with value concordance, as well as use of a decision aid.

One difficulty that has emerged in efforts to measure care consistency with preferences is a standardized approach to conceptualizing relevant terms in the decision making process. Terms such as “choice,” “preferences,” “values,” and “concordance” take on different meanings across studies, making it difficult to generalize findings (15). There is variability in the methodology of measuring these constructs and many studies do not describe a theoretical or conceptual framework as the basis of the study. The timing of assessments of preferences is identified as an area where more details would be valuable, such as distinguishing when the assessment occurred in relationship to discussions with a provider (5).

## **Methodologic Challenges and Recommendations to Assess Care Consistency with Preferences**

Challenges with the Specificity and Relevance of Documented Treatment Preferences. Concrete, specific, and relevant information about treatment preferences is important in determining whether treatments are consistent with preferences. A lack of specificity in documentation forces clinicians to interpret preferences, an approach that can result in variable interpretations (11, 16) or overgeneralizations (17-19). When patients are asked about their goals of care, they often name general goals such as living longer or improving function (20). A major challenge for clinicians is to help patients or surrogates translate these general goals into specific plans for treatment. Earlier research studies addressing preferences for end-of-life care have sometimes used more general questions such as the SUPPORT study, which inquired, "If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?" (21) The wording used in this study also implied a trade-off between the two options that is not necessarily inevitable, particularly given increased access to palliative care services. The Health and Retirement study included several separate items addressing preferences for "all care possible," "limiting care in certain situations," or being "comfortable and pain free without taking extensive measures to prolong life" (9, 22). Other researchers have incorporated descriptions that include specific interventions such as cardiopulmonary resuscitation (23). Hickman et al. have used chart reviews to assess the consistency between treatments provided to nursing home residents near the end of life and POLST form medical orders, developing decision-rules to determine whether treatments were primarily comfort-focused or life-prolonging (24).

A related methodological challenge is that in order to measure consistency with a preference, the treatment preference needs to be relevant to an actual treatment decision. For example, there are current Centers for Medicare and Medicaid Services (CMS) funded demonstration projects designed to

reduce hospitalizations of nursing home residents (25). For transfers to the hospital that do occur during these projects, it may be difficult to determine whether treatment preferences were honored. For example, if the only documented treatment preference is code status, preferences for hospitalization would be unknown if the patient experiences a pain crisis and is transferred to the hospital for management. Assessment of consistency is easier when there is more detailed information about preferences. Ultimately, decisions about whether an intervention enhances comfort, for example, are fairly subjective.

Finally, in assessing care consistency with preferences, it is important to consider whether the treatment in question is clinically indicated. For example, a patient may indicate a preference for no feeding tube. If the patient does not develop dysphagia or any clinical reason for a feeding tube to be considered or discussed, the fact that the patient did not receive a feeding tube is completely independent of the patient's preference to not receive one. It is problematic to count the absence of a treatment as "consistent" with preferences if the treatment is never indicated in the first place (24, 26).

*Recommendations:* The current MWM care consistency guideline provides examples of the type of specific preferences that may be measured, such as DNR status or feeding tube. We believe this call for specificity is a strength that will allow for higher quality measurement than assessment of general preferences such as "comfort" or "aggressive" care that are vague subject to differing interpretations. Offering to complete POLST forms with eligible patients should be the considered standard of care since POLST contains specific orders to guide treatment and because guidelines exist to assess consistency with care preferences (16, 24, 26). Structured counselling, such as Respecting Choices® Last Steps (27), provides a mechanism for translating general goals into specific treatments. The absence of a treatment should not be counted in assessment of care consistency unless there is documentation that the treatment was considered and withheld based on patient preferences.

Challenges with Documentation. In order to measure whether care provided was consistent with preferences, treatment preferences must be documented clearly in the medical record in a systematic, standardized format. The variety of electronic medical record (EMR) products and lack of inter-operability across settings presents real challenges in tracking recorded preferences to determine whether they match the treatments provided (4, 12, 28). Specific treatment preferences, such as “no tube feeding,” may be documented in a provider visit note but may be very difficult to find weeks or months later when the information is relevant to patient care. Efforts to assess the consistency between preferences and treatments are significantly compromised when information about documented preferences is inaccessible.

Recommendations: Specific provider orders reflecting preferences, such as “do not resuscitate” or “do not hospitalize,” are easier to assess if systems are in place to make this information accessible in the EMR. This information must be recorded in a consistent format and location in the patient medical record – we recommend doing so in a separate Advance Directives tab. Scanning advance directives into a standardized, easily accessible location in the medical record can improve rapid access to preferences when clinically relevant. When possible, alert or “flag” systems should be used. The use of standardized forms or order sets that document specific treatment preferences should be encouraged, e.g. – Physician Orders for Life Sustaining Treatment (POLST) forms. The widely used POLST paradigm describes four goal-driven choices for medical interventions that include specific instruction about interventions including hospitalization, ICU admission, intubation and mechanical ventilation (16). POLST orders should be used as the basis of inpatient hospital orders once a patient is admitted.

Challenges with the Stability of Documented Preferences. The timing of assessment and documentation of patient preferences is critical in assessing consistency. It may be difficult to predict what treatments may be desired in a future state, leading to patients revoking previously stated wishes as their condition changes (29, 30). A recent review directly addresses the issue of stability of patient



preferences over time. Auriemma and colleagues (2014) examined studies that had collected longitudinal data on patient preferences. While a majority of patients in these studies did have stable treatment preferences over time, about 20-30% of people in each study reported changed preferences for treatment, including desiring either more aggressive or less aggressive treatments. Patients who had completed advance directives were found to have more stable preferences over time (31).

In many cases, patients will lose the capacity to make medical decisions and will have treatment preferences determined by surrogate decision makers. In fact, 47% of hospitalized older adults (31) and 70% of older adults at the end of life require a surrogate (9). In some cases, surrogate decisions are informed by advance directives that were previously completed by the patient; consistency can be assessed by whether the patient's advance directives were followed (9, 32). In other cases, patient preferences for a particular treatment may have not been determined prior to loss of capacity and surrogates are left to make decisions based on ethical guidelines such as "substituted judgment" and "best interests" (33). In such cases, it may be more appropriate to assess concordance with the surrogate's preferences for treatment. Additionally, particularly in some cultures, decision making may be more group and community focused than individually focused (34). It is important to consider that goals of care or realistic treatment options may change after a patient loses capacity. Patients cannot always anticipate or plan for future decisions or determine their future preferences for conditions they have not yet experienced (11, 35). The POLST paradigm, and other mechanisms to designate legal health care representatives, also anticipates this possibility by giving legally authorized surrogates the authority to change the form after the patient loses capacity. Such changes by a surrogate might be due a legitimate change in treatment possibilities and goals.

*Recommendations:* Ensure documentation is reassessed periodically and reflects the current preferences of patients when possible. We recommend at least annually and when the patient's condition changes. Assessments of consistency need to take into account the possibility that a patient

may have changed his or her mind and requested alternative treatment. In some cases, assessing consistency with preferences may include decisions not previously documented in advance directives by the patient but instead made by clinicians and surrogates.

Challenges with Treatment Timing and Non-Events. Another challenge relates to decisions to withhold indicated treatments in accordance with patient preferences. Non-events, i.e.-not delivering a treatment, are rarely documented in the medical record so it may be difficult to retrospectively determine when a potentially clinically indicated treatment is withheld due to care preferences (24). For example, in our CMS nursing home demonstration project (25) there are often decisions not to send a patient to the hospital in accordance with preferences for comfort care. However, it is difficult to find documentation of this decision making process. Also, if a treatment is provided and then withdrawn (e.g.-extubation) after previously documented preferences are made known, it is debatable whether this “counts” as consistency with documented preferences or as a medical error. Contextual features may influence how care consistency is evaluated.

Recommendations: A recognition of the importance of giving credit for appropriate “non-events” and “non-interventions” is important. Implement prospective or real-time data collection strategies to capture decisions to withhold interventions when possible. When treatments are withdrawn, information should be obtained about the context of the treatment decision to determine whether the withdrawal is consistent with patient preferences.

Challenges with Calculating Rates of Consistency. A variety of strategies to measure “agreement” between recorded preferences and actual treatments have been utilized. Several research studies have used matching methods such as Chi Square analyses and regression models to calculate the relationship between treatments and preferences. Other methods include structural equation modeling, correlation, and use of the kappa statistic (5).

Recommendations: Consistency in measurement approach will be needed if quality measurement will be used to compare different health care providers. In the clinical setting, it may be most appropriate to use percent agreement because it is clear and immediately interpretable by clinicians as well as administrators (5).

Table 1 here:

## **Conclusion**

Measuring *Care Consistency with Documented Care Preferences* does matter, as it is a relevant and critical measure of providing quality patient-centered care. There are clearly challenges to the implementation of this measure which need to be considered. A summary of all the recommendations in this section is provided in Table 1. To be useful at the point of care and to be tracked, treatment preferences must be recorded in a consistent format and location in the medical record such as a specific Advance Directives tab. This may require investment to adapt current medical record systems. Further, while the concept of receiving care that is consistent with preferences is fairly broad, in order to be measured, concrete and specific orders must be the focus. Without this, there could be wide variety in interpretation as to whether or not a given treatment path was consistent with patient wishes. Patient preferences may not be stable over time, especially as a patient's clinical condition changes. Preferences should be reviewed and updated regularly to reflect a patient's current wishes for care to the extent possible.

There are a number of considerations related to measurement of concordance. A strategy must be developed to record instances where a clinically relevant treatment was considered and not pursued consistent with patient preferences, i.e.,-withholding interventions or non-events. Also, use of a

consistent metric is key in order to promote tracking progress over time and quality between providers, for example, percent agreement.

Multiple studies, in a variety of populations, have revealed that treatments do not always match stated preferences. If the care consistency quality measure is implemented across health care providers, as intended by the MWM project, then larger scale studies can be conducted to provide insight into inconsistencies. Honoring patient preferences for treatment fulfills the promise of the advance care planning paradigm. The responsible integration of this care consistency quality metric into health care settings is an important step forward.

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**Table 1: Summary Recommendations to Measure Care Consistency with Documented Care Preferences.**

<b>Recommendations for implementation of the MWM Quality Measure: <i>Care Consistency with Documented Care Preferences</i></b>
Document specific treatment preferences in the medical record, ie-“do not place feeding tube” vs. “comfort care”
Record treatment preferences in a consistent format and location in the patient medical record
Review and update preferences regularly to reflect current preferences as clinical condition changes over time.
Implement prospective data collection strategies to capture decisions to withhold interventions or non-events.
Adopt a consistent measurement approach in order to compare within and among health care providers, eg-% agreement.